

Vol. III No. V August 1992

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆



WINTER READING

PM

ACTing UP in Amsterdam

ACT UP HAVE BEEN A STRONG PRESENCE AT THE VIII INTERNATIONAL CONFERENCE on AIDS, held two weeks ago in Amsterdam. Their involvement began with the demand that the conference expand access for PLWHAs. There have also been ACT UP speakers at several sessions I've attended, including the opening ceremony. On the first day of the conference more than five hundred people marched through the centre of Amsterdam to draw attention to travel restrictions against people with HIV. They delivered black coffins to embassies and declared that "AIDS has no borders".

At the opening of the conference, the US immigration restrictions which had caused the conference to be moved from Boston to Amsterdam came in for sharp criticism from both ACT UP and keynote speakers. The conference was told by Richard, an ACT UP representative, that, at that moment, Boston ACT UP were holding a vigil at the original site of the conference. Richard also reminded us that Amsterdam was the home of Anne Frank, a victim of the Nazi holocaust. He drew a parallel with the US: it is a holocaust when a government turns its back while a quarter of a million of its people die, he said.

In a moving speech, Tomas, a Latinamerican HIV+ man, resident in the US, appealed for emotional and practical support for foreign-born people and said that restrictive immigration laws serve only to force people underground. He also said that in the US, Latinamerican refugees have been forcibly tested. Tomas told the conference his full name, flight number and date of return to the United States and issued a challenge: "I defy George Bush to prevent me from returning to my home in America."

ACT UP also called for a boycott of Astra pharmaceutical products, except for Foscarnet. They urged this action because Foscarnet, which has been available for several decades and is, apparently, cheap and simple to make, is prohibitively expensive for PLWHAs. ACT UP are calling for the boycott to force Astra to lower the price. The opening ceremony was picketed by ACT UP and Astra's stall in the Exhibition Hall was attacked. ACT UP has also been calling attention, during the course of the conference, to other drug companies' profit-making from AIDS.

--Jill Sergeant

DEAR *TALKABOUT* READERS,

For the next two months *Talkabout* will be in the capable hands of David James, Jeremy Nicholas and Robert Ariss. I'm playing roving reporter for a while, first in Amsterdam and then East Africa, where I'll be visiting PLWA organisations. You'll hear more about this trip in future issues of *Talkabout*. I'm also having a holiday. Expect a colour centrefold on lions and wildebeest.

Signing off from Amsterdam with love and solidarity,

Jill.

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This Month's Cover

by Phillip McGrath. Experimental AIDS drugs and 'new age' thinking... Find out more by reading our special *Winter Reading* section, starting on page 11.

Bactrim versus aerosolized Pentamidine

THE HISTORY OF WHAT IS THE best choice for PCP prophylaxis illustrates that sometimes objective 'science' can be influenced by other factors. Three years ago there was a widespread belief amongst treatment activists in Australia, including myself, that aerosolized pentamidine was the best known form of PCP prophylaxis. We thought that the reason for its unpopularity in Australia had something to do with its cost when compared to other forms of prophylaxis, its unavailability and medical conservatism.

In the United States, certainly, aerosolized pentamidine became the treatment of choice. Gradually, evidence became available that for people who could tolerate it, Bactrim was an equal, if not superior, prophylaxis for PCP. It took a long time for this to be accepted, though still not totally, in the United States because of these other factors. The data showing the effectiveness of aerosolized pentamidine as prophylaxis for PCP was United States data. It was produced from what was called a 'community' trial. The ownership of this data and a belief in the 'community' trial mechanism led to a reluctance to give appropriate weight to other evidence. There were also feelings that pentamidine was a newer and, therefore, better drug.

Further evidence is now available supporting Bactrim (as it is best known - its proper name is trimethoprim-sulphamethoxazole) as being probably more effective than aerosolized pentamidine. This data has been recently

published in the journal *AIDS* and is based on a retrospective (ie historical) study done at St Vincent's Hospital in Sydney. In this study all cases of PCP treated at St Vincent's Hospital from January 1986 to August 1990 were reviewed. People who commenced prophylaxis after a first episode of PCP were compared (this is known as secondary prophylaxis - taking medicine to prevent a recurrence of active disease). 60 people commenced 'Bactrim' prophylaxis, 81 commenced aerosolized pentamidine and 38 no prophylaxis.

Of those who relapsed (ie had another active bout of PCP), there was 1 (1.7%) in the Bactrim group, 31 (42.5%) in the aerosolized pentamidine group and 21 (55.1%) in the 'control' (ie no prophylaxis) group. From this data it certainly appears that 'Bactrim' (*t r i m e t h o p r i m - s u l p h a m e t h o x a z o l e*) is a more effective form of secondary prophylaxis than aerosolized pentamidine.

More data supporting early intervention

EXISTING DATA ON AZT IS sufficient to show that:

- i) AZT prolongs survival in people with AIDS;
- ii) that AZT delays progression of HIV disease in people who are HIV+ but don't have AIDS.

The question of whether early intervention prolongs survival is more controversial, particularly after data from the United States Veterans' Affairs study, which, while confirming i) and ii) above, was inconclusive on whether early

intervention prolongs survival.

This question is of course vital for many people with HIV - 'do I take AZT now when I'm well or do I wait until I'm sick'. Personal perspectives in *Talkabout* have featured this dilemma.

One method of building up evidence about the effectiveness of pharmaceuticals is the clinical trialling of small sample groups in the community. Another important method is based on what are called 'observational' studies - that is looking at the use of the drug in clinical practice after approval. This usually involves a larger sample group. While these studies can have some biases, they often provide important information about effectiveness and they are sometimes the way in which adverse reactions not identified in smaller clinical trials are documented.

One such observational study involving 2162 subjects in the United States provides more data on the questions of early intervention with AZT. This study was published in the April 16 issue of the *New England Journal of Medicine*. The results of this study show that early treatment with AZT and PCP prophylaxis improves survival in addition to slowing the progression to AIDS. After adjustment for the effects of PCP prophylaxis, AZT alone improved survival and slowed progression.

-- Ross Duffin

AMSTERDAM

VIII International Conference on AIDS

ON THE SECOND DAY OF THE VIII International Conference on AIDS, a special presentation was held called "Multiple Losses: Impacts and Solutions". The audience was invited to share their experience of multiple loss and four people were chosen at random, from those who volunteered to tell their stories. The first was Barbara, a woman from the Italian Red Cross, who worked in a hospice for PWAs. She said she had been working there for five years and seen hundreds of people die.

Before Barbara left to come to the Conference, her patients had asked her to bring back good news. But, she told us, she dreaded going back to work - just a day or two after flying back to Italy from Amsterdam - because what could she tell them? She had no good news. There were no major breakthroughs in research to report. Nothing much had changed, in fact.

She was visibly distressed. She appealed to the panellists, to all of us present: what could she say to those young men waiting in her hospital ward? It was a cry from the heart, and a timely reminder of why we were all here. In the press of more than 10,500 delegates, the blue and white, plastic and chrome stands of Burroughs Wellcome, Abbot Diagnostics, Astra Pharmaceuticals, et al, amid the maze of poster presentations in techno-speak - well, it could have been a conference on just about anything. The human element was hard to find.

I was also reminded of why I was here. It's a pretty

overwhelming responsibility, reporting back on a conference of this size. Where do I start? Well some of the Aussies present divided things up amongst ourselves and what I can offer here is our collective impressions and my own thoughts on sessions I've attended.

Despite Barbara's pessimism, it's not all bad news. On the treatments front, Ian McKnight (AFAO Treatments Project) has asked me to convey these main points.

- Combination therapy is continuing to show considerable

...what could she say to those young men waiting in her hospital ward? It was a cry from the heart, and a timely reminder of why we were all here.

promise, and there is some indication that AZT is beneficial for asymptomatic HIV+ people with high T-cell (or CD4) counts. He believes, on this basis, that we should be seeing two changes in Australia: AZT made available for people with above 500 T cells; and increased availability of combination therapy.

- The evidence for the benefits of therapeutic vaccines is looking pretty good. The bad news, for some, is that it looks like people have to have a reasonable level of immune function for the vaccines to be effective. The trials conducted have mostly been on people with counts of 400-500, al-

though one community based trial included a wider range of participants, some with counts as low as 200. Ian's recommendation on this is that we need to get some trails up and running in Australia pretty quickly.

- It is becoming clear that it is now easier to predict HIV/AIDS disease progression. (This was the depressing session.) People infected with the *Syncytia Inducing* strain (SI, see May edition of *Talkabout*) progress to AIDS more quickly than those who are not. (This may help explain long term survival). It looks probable, however, that people who do not have SI, HIV will mutate to SI as T-cells decrease, perhaps at a count of about 200. After this, there is likely to be a rapid deterioration in T-cells.

The organisers of this conference claim to have made a considerable effort to engage the participation of affected communities. It seems that the taste of the last International conference (Florence, 1991) is still pretty sour. The emphasis at Florence was science. Here, a major portion of the time and space is devoted to community based responses to HIV and AIDS. There are four tracks: Epidemiology, Basic Science, Clinical Science and Care, and Social Impact and Response (which is the one I've chiefly attended).

Conference organisers consulted with community based and PLWHA based organisations world-wide, and people from developing countries. Improved

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DEADLINE FOR THE NEXT ISSUE

August 17

Send contributions to PO Box 1359 Darlinghurst, NSW, 2010. Call Jill for the date and time of the next Newsletter Working Group meeting.

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representation of women was also high on the agenda.

I feel that the organisers have done quite well in achieving their goals. Certainly there is a high African and Latinamerican presence, (both in attendance and in the program) and women's issues are very well represented across the programming. There is, however, a noticeable shortage of Asian and Pacific delegates and an overabundance of North Americans. Arab nations, on the whole, are conspicuous by their absence. Indigenous people's issues are being addressed in more than one forum, but representation of Australian Aborigines is very low. Developing countries are once again drawing our attention to their needs. Will anyone ever listen? There is a private lounge for people with HIV.

Browsing through the huge hall of poster displays, I've been struck by an overall unity of approach among community-based organisations. Normally in Australia we hear only the bad news about other countries' AIDS strategies and experience, so it has been encouraging to see in countries as far afield as the UK and Nigeria, a similar openness in addressing education and care issues. Similarities include: empowerment; openness about people's sexual practice and willingness to be frank about sex; community education programs to overcome stigma; explicit youth education programs and material; peer education; outreach to just about every at risk subculture you can think of (except the only transsexual information was from

Australia); ethics around HIV testing; gay venues and beats outreach; HIV+ people as educators; PLWHA self-help initiatives; exploration of alternative treatments.

A striking example, for me, of how we are doing at a global level, was that in Cote D'Ivoire (West Africa), condoms are advertised on TV and radio - unlike in Australia. Another was a photograph I saw of a union leader in Nigeria demonstrating condom use to long distance truck drivers. (I had to be told it was a dildo.) Try that for size, Bill Kelty.

The poster displays have also been a good opportunity to meet people and chat about our various projects and priorities. The formal

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abstract presentations 'round table' discussions are generally a bit alienating and don't offer much in the way of participation. The exception, for me, was the "Multiple

Losses" presentation.

Other people I've spoken to about this presentation have also been impressed. It was conducted by four very calm, reasonable and spiritual individuals who talked about various spiritual, emotional and cultural ways of dealing with the grief of multiple loss. It was a very healing session. Someone commented to me that it should have been compulsory for all conference delegates.

It's not surprising that some of the strongest impact at the conference has come from HIV+ speakers. PLWHAs have been on the speakers panel of most of the sessions I've attended and have always made powerful statements about what their priorities are and how they're affected by all the

science and technology being discussed in obscure detail on the other side of the main hall.

Compared to previous conferences, quite a lot of attention has been given to alternative therapies. There's been a predictable tension between the 'love your disease' advocates and those who are interested in alternative therapies but think love is no substitute for clinical trials. Of course, there are many shades in between, and so far the tension hasn't developed into outright conflict.

There is a consensus, though, that more research is needed into a variety of alternatives. An HIV+ speaker at one session argued that the disadvantage to using alternative treatments is their lack of regulation - we need to know more about their effectiveness, purity, dosage levels, toxicity, etc, he said, and controlled clinical studies are the way to get better information.

Some reports have been given about research to date on vitamin C, garlic, Compound Q and Chinese medicine, but suggested that the spiritual dimension of their traditional healing was as important as the herbs, which might make it less helpful to people outside their community.

A forum on nutrition and HIV was rather poorly attended, which perhaps reflected the speakers' contention that nutrition is a neglected aspect of HIV/AIDS management and treatment. The session covered an enormous range of issues and involved the most genuine audience participation I've yet seen here. Issues covered included: malnutrition, third world countries, nutrition as prophylaxis, megadoses of vitamins, treating diarrhoea, the symbolic significance of food, candida, meat eating and the

conference catering. It was concluded that food is a vital political issue that should be placed firmly on the agenda of the next international conference (Berlin 1993).

FOOD WAS NOT THE ONLY ISSUE that conference participants have perceived to be neglected. Young people have put out a press release saying that their issues are not being adequately addressed at the conference. Sex workers have said that the conference has not adequately addressed human rights abuses against HIV+ prostitutes. They requested that conference delegates wear a black armband with a red thread in protest at the killing of 25 HIV+ sex workers in

Kathy Kum-Sing, representing Aboriginal Australia at the Indigenous Peoples' forum, called for a stronger representation of indigenous people in Berlin and a commitment to tackling their issues.

Burma. (They were injected with cyanide after being deported from Thailand). They also organised a protest march through the conference on Thursday. By this time I think the conference was well aware of the atrocity; it was raised in a couple of unrelated sessions that I attended and was condemned in the Plenary on Human Rights. A speaker in this session said he believed that human rights should be given more attention at the next conference. Kathy Kum-Sing, representing Aboriginal Australia at the Indigenous Peoples' forum, called for a stronger representation of indigenous people in Berlin and a commitment to tackling their issues.

A talk by James Curran from

the US Centres for Disease Control (CDC) was interrupted by women protesting the CDC's official definition of AIDS which still excludes woman-specific conditions.

Some participants feel that gay issues have been inadequately addressed or excluded from the relevant sections. A forum on the impact of HIV on families did not consider gay "families of choice"; a discussion of discordant couples had no gay representation on the panel.

John Mordaunt of *Mainliners* in Britain challenged future conference organisers to involve injecting drug users (including ex-users) in conference planning.

Doubtless there are plenty of other controversial issues that I haven't yet heard about. Because it's such a big conference, people may have completely different impressions of its success or failure just depending on which sessions they've attended. Some think it's great, others very poor. But clearly, for many people, there's a hunger for information and resources and sharing of experiences.

I'll close with an example. Some thoughtful person from Melbourne brought 150 of the Aboriginal "Everybody's Business" posters. A crowd descended like hungry wolves when she opened the box and they were gone in seconds.

-- Jill Sergeant.

Some tapes of conference sessions will be available from PLWHA for borrowing in a few weeks, as well as photocopies of articles and other material of interest.

THE YOUTH HIV PROJECT

THE FIRST YOUNG PERSON under the age of 21 was diagnosed with AIDS in October 1985. Australian statistics show that youth make up 2% of known infections and since approximately 27% of HIV infected adults are in their 20s, we can safely assume that many were infected in their teens.

The *Youth HIV Project* arose from the concerns expressed by youth workers and health professionals in the late 1980's that Australia was on the verge of an epidemic of HIV amongst young people. Experience in North America and Europe suggested that youth were making little effort to protect themselves from HIV infection, and had the highest rates of risk behaviours.

Yet, after considerable consultation and looking at the available research, it was clear that objectively little was known about HIV positive youth - neither how their sexual and drug use behaviour was affected by the diagnosis, nor the personal impact of the diagnosis. There were many concerns expressed that young people may deal differently with problems that arise out of being HIV positive, but no objective information which might focus these concerns more. As well, the issues HIV presents for Australian youth could easily be very different from those other developed countries.

We subsequently piloted and have been using a questionnaire and interview which covers a number of areas related to young peoples' lives including family background, education,



relationships, coping style, emotions and attitudes, injecting behaviour, coping with sexuality for those who identify as gay or lesbian and survival on the street for the homeless.

The *Youth HIV Project* is being conducted by the University of New South Wales, the Prince of Wales Hospital and St Vincent's. The research investigators are Professor Brent Waters, Mr John Howard and Dr John Ziegler. The project staff are Guy Noyaux and Kay Roy.

The *Youth HIV Project* will run for at least three years which will allow us to talk with young people on several occasions over that time. The interviews are conducted in an accepting, non-judgemental and friendly atmosphere. After completing the first year of the study, we have seen young people from various backgrounds:

- young men who have sex with men who are either from the scene

or non-scene

- young women with bisexual partners
- young IV drug users
- young homeless people
- students and unemployed people
- people from interstate - South Australia, Western Australia and Victoria

While it is too early to comment on the results of the study some important issues which have emerged already are:

- relationships - falling in love, whether to enter into a relationship again and if so how or whether to tell their partner about their seropositivity;
- casual partners - balancing the needs of informing your partner of your seropositivity and your needs for privacy, fears of rejection;
- career choice - where to go from here, is it worth keeping going with education and vocational training;

Continued on page 10

Talkback



Grief and loss

IN THE PAST THREE MONTHS I'VE lost seven friends, two within the same week, two (in U.K.) whom I'd known for 20 years, two who found time to say hello to me in my own locality. I miss the wave from one of them from his balcony as I crossed the road or when he had a quiet drink in a local pub. Each time I pass his building a tear comes to my eye. The other, well, I only knew him because we would hold each other and kiss (when it was not so acceptable to do so in earlier years), at Mardi Gras or by chance meeting near the Oxford Hotel. I would like to thank his carers who phoned me to tell me he had died. It was really appreciated and, thanks to these people, he had someone there to the end, so it is hoped his passing was easier. The last of my closest friends at this time of writing is dying. His family gave me the privilege to say goodbye only yesterday, as he had been very private about having HIV and AIDS. He and his sister always found time for me when I, too, stumbled and lost touch with friends dying around me, always with a glimmer of hope to survive against the odds, yet I feel guilty that I could have given more than they gave me. With a break in my social life, the reduction of venturing out, I see an ever increasing gap as friends die, and a new-found isolation is now a punishment for people of my age group (late 40's) who have

survived, more by luck than fortune. What will there be left for us, as we grow older knowing that our friends have gone long before us? and who will be our friends when old age (if I ever get there), befalls us? Or will we be doomed to live up to the old adage, when you grow old no-one wants you? I've reached that now! I have by luck, rather than skill and, I suppose, willpower survived till now, but there comes a time when all that runs out. Then what?

People are dying all around me to an extent that my grief is never ending. It's one to the next. Each time it gets a little harder to cope with the added stresses that grief brings. Will I have friends to talk to when I grow older? Who will help me next time I'm ill? I now rely on an ex-lover to help when the going gets tough, yet I only have myself to blame. In striving for independence, I over indulged myself to independent isolation, and with my life-threatening disease slowly taking away my full independence I have found humility by the courage of people living (and dying) with AIDS. I salute you all, because in your unity of common cause you have been able to show me the way too, it's just that I miss seven friends who are no longer there, who had time in their suffering to say 'Hello, I care too!' Thank you all.

Michael J. Winter.

Social Security?

BEING HIV+ CAN SOMETIMES put you in never-never land, especially with departments like Social Security.

Recently my lover's health dropped and he was given a six week doctor's certificate. His next "Job Start" renewal arrived with a letter explaining that because of his medical certificate he only had to post it back on this occasion. This he did. It was returned as not acceptable having arrived on the wrong date. I went in on his behalf to sort out the problem but was promptly told that it was not my business and due to his privacy the officer could not discuss it or accept his renewal form. I then had to take my lover in and, after making an appointment with the resident social worker, was informed we only have two options. One: to post the renewal in, but it has to arrive on the exact day; or two: take it in personally. All this when he is not well and is supposed to be as stress-free as possible.

Which brings me to the real problem here. There are no boxes to tick or pigeon holes to put people with HIV in. When he is well he looks for work (in a city running at 12.5% unemployment) and has a heap of unsuccessful job applications to prove it. He is sometimes not well enough to look but not really sick e.g. when starting AZT he was nauseous and sleepy. He also has a reasonable amount of appointments which

take up a lot of his time e.g. eight weeks of dental work, monitoring his health and affects of AZT, waiting sometimes one and a half hours at hospital for medication.

He is not ready to be pensioned off and a lot of the time looks for work. There appears to be no compassionate system that allows him more flexibility. At various stages social security have insisted on knowing his exact health status, even forcing him to have his doctor fill in a health questionnaire or else face losing the benefit. We have an excellent doctor who is trying to keep our options for the future as good as possible.

I have always felt that HIV/AIDS is very adequately catered for (except perhaps drug trials etc.) and am very thankful for that.

I am also HIV+ and because I receive a small amount of interest (a lot less than the dole) am not on social security.

*Terry,
South Australia.*

Impressed

LAST MONTH WHEN I RECEIVED the first "new look" *Talkabout* I was truly impressed. The new cover, the printing, the photos, the diversity of articles and just about everything in this new look is great. It's interesting and easy to read and professionally done.

A big progress since the first issues of *Talkabout* a few years ago.

I guess if not the whole credit, then certainly a big part of it should go to one person, whose dedication to *Talkabout* is to be admired. Good on you Jill!

I would also like to congratulate Gabby, the new coordinator, who seems to be

very enthusiastic, with lots of goodwill and ideas. Certainly a needed change to the position she is now holding. Finally, to the newly elected committee, I wish good luck, patience and tolerance.

Eyal Levinson

HIV/AIDS Confidentiality

I REFER TO THE ARTICLE IN THE July issue of *Talkabout* regarding the HIV and AIDS confidentiality provisions of the Public Health Act.

I am sure that your readers would be interested to know that the Department is preparing an official circular to be distributed to health care establishments and workers throughout the state, outlining and explaining the meaning of these provisions. The circular will also contain a guide to practical steps that should be taken to safeguard confidential patient information.

In addition, we are preparing an article suitable for placement in professional and union journals.

While the Public Health Act appropriately contains special provisions in regard to the confidentiality of HIV and AIDS records, it should be remembered that the professional standards and ethics that apply to all health care workers require information relating to individual patients to be kept confidential.

*Yours Sincerely,
David Lowe
Director, AIDS Bureau*

We welcome your letters.
Send them to:
**Talkabout, PO Box 1359
Darlinghurst, NSW, 2010**

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- grief - how does a young person cope with an older partner who is having HIV related emotional and health problems;
- procreation - disappointment over lost ability to have children;
- the upside - positive changes in a young person's life as a result of being HIV positive;
- telling the family - issues with parents and siblings;
- sexual behaviour - the difficulties of negotiating and practicing safer sex and drug use;
- discrimination - expected and unexpected;
- coping - emotional adjustments to diagnosis and illness progression;
- sharing - whose and what support has been helpful.

We will be presenting a preliminary report of the first stage of the study at the 5th National Conference on AIDS at Darling Harbour during November 1992.

We are grateful to the many young people who have already responded and to their carers and health workers who have supported, encouraged and passed on information about the Project.

However, we need to talk to more young people who are HIV positive in order to be of assistance to all young people living with HIV/AIDS and to health workers in the field, to help design and implement more effective prevention strategies, and to develop more effective management programs.

If you can help please call Guy or Kay on 399 4999 or 399 2968 (or if dialling from interstate please call (02) 399 2966 (call the operator to reverse charges). We pay young people \$30 for an interview.

Brent Waters

Winter Reading

This month we review a selection of books that deal with issues surrounding people living with HIV/AIDS. Read on...

Catastrophic Rights Experimental Drugs and AIDS

Author: John Dixon
Published by: New Star Books,
Vancouver, Canada, 1990
131 pages, paperback

'THE LOGIC OF RIGHTS MAKES possible the genuine adjudication of conflict between individual and public claims, and this is, in our present circumstances, a painfully missing capability ... of our regulatory systems.'

The regulatory systems referred to here are the Food and Drug Administration (FDA) in the US and the Health Protection Board (HPB) in Canada. These agencies set the standards for the drugs that go on the market. In doing this, they exercise their governments' responsibility to care for and promote the public interest by, for example, controlling the use of medicines by making sure that drugs do what they are supposed to (i.e. that they are effective) and that they don't do more harm than good (i.e. that they are safe).

This is a form of paternalism, a limitation of the freedom of people 'for their own good'. It involves the carefully controlled study of the safety and efficacy of new drugs through experiments that follow the randomised, double-blinded standard. This immediately makes obvious the close link between the interests of public health and the interests of medical science. The principal of paternalism means that, it is, after all, because 'father

knows best' that he has both the right and the duty to limit the freedom of his children 'for their own sake'. Similarly, it is because 'doctor knows best' how to treat sickness that the medical industry has an authoritative role to play in governing therapy.

Bodies such as FDA and HCB have as a main objective the wise and fair management of limited health care resources. A relevant consideration here is that the management of drugs for conditions like HIV/AIDS works to maintain individuals as productive members of society.

This, in summary, is the background against which Canadian philosopher John Dixon argues in favour of increased access to therapeutic autonomy for people with AIDS. His book *Catastrophic Rights, Experimental Drugs and AIDS* develops the notion of catastrophic rights along the following lines.

'The clear statement of a public interest is usually sufficient to set aside the interested claims of individuals, but to think it must always be so is an error grounded in the confusion of interests with rights. In our moral and legal tradition, some individuals' interests are given a special status as rights which may act, in at least some settings, as 'trumps' over ordinary dominant public interests.'

Dixon's elaboration, in short, is

centrally concerned with the conflict between the rights of the HIV-infected individual and the interests of public health. This, the author argues, is the case with PLWAs whose freedom to try to save themselves by whatever means they deem appropriate constitutes what the author terms a *catastrophic right!* The force of this right overrides the paternalistic barring of access to unproven treatments. Because of the therapeutic autonomy, this restriction can't be in the name of 'their good' since, in the face of AIDS, the deprivation may hasten death, i.e. cause upmost harm to the infected person.

The argument becomes thorny when economic considerations enter. Since most experimental drugs are developed by pharmaceutical companies, the person with AIDS is effectively demanding enhanced access to that which is owned by others. Dixon takes us through the awesome technicalities involved in government funding of experimental drugs in North America, (for example, the fact that in Canada, it is unlawful to sell experimental drugs). For Dixon, legal policy notwithstanding, governments have a *moral* duty to provide for very expensive drugs if these may be integral in the treatment for a life-threatening disease. His argument is that no-one should be deprived of essential

medical care because of their inability to pay for it. This is a moral principle that deems it inappropriate and cruel that the sickroom should be an arena for the forces that have free reign in the marketplace.

The strongest argument against PLWAs' use of experimental drugs outside of controlled studies is that it may compromise the scientific study of their effects. To quote Dixon:

'If we are to have medical progress we must have science; and if we are to have science we must have experimental controls. Unhappily, the antiseptic notion of control of studies necessarily translates into the troubling reality of the control of persons.'

This translates directly into a set of conflicting claims: on the one hand, the person living with AIDS is demanding access to a new drug; on the other, clinical science needs a control population of PLWAs who will receive not the drug that is being studied but another substance which will act as the control. This scientific imperative is justified on the grounds of public interest, i.e. in terms of developing effective treatments for people who will develop AIDS in the future and towards whom the present therapeutic system has an undeniable responsibility.

Dixon's exposition of this conflict is multifaceted, and he goes to great lengths to do justice to the competing values of each side of the debate. He ends up canvassing a commitment to the notion of catastrophic rights as a tool with which to move the therapeutic system to (further) reform. From this commitment flow important consequences such as research initiatives from within the PLWA community (already happening in the US), a view of the state as morally responsible rather than simply as a neutral regulator, and a view of medical knowledge as an

instrument for human good rather than an end in itself.

Dixon's humanism, which the above summation of his arguments has made appear idealistic, does not stand alone. His treatment of the legal and moral complexities of PLWAs' right to 'enhanced therapeutic autonomy' is eloquent, thorough and above all pragmatic. He includes journalism, excerpts from court hearings and private communications to illustrate his points. His reasoning is

meticulous while his text never loses its sense of immediacy. His sentence structure tends to be over-elaborate but, then, stylistic excesses are something of a prerogative for academic moral philosophers. In conclusion it must be said that the kind of critical analysis that Dixon undertakes barely begins to compensate for the silence on AIDS from the ranks of professional philosophers.

- Kosta



Petrea King. PHOTO: JAMIE DUNBAR

Quest For Life

Author: Petrea King
Published by: Random House
Australia, Sydney, 1992
400 pages, paperback

WITH 400 PAGES, PETREA KING'S new revised edition of *Quest For Life* is not a book you are likely to flick through in the waiting room of your doctor. However, the multitude of topics and the detail in which they are addressed seems to justify the volume. Creating the best environment for healing, stress and relaxation techniques for living well (including recipes for healthy foods), the value of support groups, meditation and

visualisation are some of the issues touched upon.

The author, who has survived a life-threatening illness herself, skilfully interweaves factual information with personal and other case histories to illustrate her message. She uses an easy to understand language and avoids where ever possible medical/technical terminology.

The multitude of issues addressed may be a bit disappointing for readers who are specifically interested in HIV and/or gay-related issues. For instance a chapter entitled "What about children" will be somewhat

irrelevant for most gay readers.

The author similarly fails to include some HIV specific issues like fear of contagion and discrimination, which is a lot less prevalent among cancer patients, and possibly one of the reasons why many PLWAs publicly maintain the story that they have cancer, rather than AIDS.

Repeatedly, people are advised to closely co-operate with their doctors, this ignores the fact that knowledgeable AIDS-doctors are still somewhat hard to find in parts of this country. Very positive, however, is the author's attitude of self-empowerment, reiterating that it is you, the patient/client, who makes the decision and not the doctor.

On the whole the author maintains a very positive, affirmative view of life and death, putting all the decision making power in the hands of the individual.

Like most *how-to* books *Quest For Life* suffers from the old dichotomy that unless you already have some knowledge and skills in the area it will be rather difficult for you to learn meditation or how to improve your self-esteem from a book alone. However those readers who are already familiar with "New-Age" thinking will find this book to be a powerful reinforcement of their motivation.

A big draw-back is that although some reference is made to AIDS Councils no contact addresses are given. PLWA groups are not even mentioned by name. However, the name and address of the "Quest for Life Foundation" is given at the end of the book.

Further information about PLWA organisations is obtainable by calling the foundation.

Repeated references to the founder of a certain religion, namely Jesus, left me with a bit of a sour taste in my mouth, but that

may be due to my personal belief system and other readers may welcome the reference. To be fair I should mention that Petrea invites readers to use whichever deity is appropriate, only giving Jesus as her personal choice.

Quest For Life is certainly not a novel and therefore not designed to be "good" entertainment. It is separated into different issues. In order to maintain comprehensiveness of individual chapters, issues relevant to several topics are duly mentioned in all, making the text sometimes repetitive.

In conclusion, *Quest For Life* is not the new PLWA "Bible", with a copy to be placed under everybody's pillow, but the author could have done a lot worse. I certainly recommend it for those with an affinity to New-Age ideas. As far as *how-to* books go, 7½ out of 10.

- Matt Bradshaw

Against The Odds

Authors: Peter Arno and Karyn Feiden

Published by: HarperCollins, New York, USA, 1992

314 pages, hardback

I BEGAN READING *AGAINST THE ODDS* the day after I took part in the ACT UP demonstration demanding approval for ddC. As a postlude to the protest, I want to kidnap Minister Peter Staples and those clowns at the Therapeutic Goods Administration like Brian Hillcoat, put them to bed and read them all 314 pages as a bedtime story, appendices and everything. Then watch them get nightmares.

Against The Odds is about how people with AIDS in the US have transformed the way a drug is taken through its paces before ending up in people's bodies. It is a very complex story, which Arno and Feiden tell

very well.

There are 3 broad stages in the development of a therapeutic drug: *screening*, where a test-tube compound is assessed for anti-HIV effects; *tralling*, where the drug is tested in humans to find optimal doses and to make sure side effects are tolerable; *evaluation*, where the country's drug regulatory body examines the data in order to license the drug for marketing. In most industrialised countries there is a fourth stage: *remuneration*, where the government decides how it will pay for the drug. In the US, because there is no national health care system, there is no fourth stage and remuneration is the sole responsibility of the patient.

Arno and Feiden show how regulation of drug marketing came about solely as a response to dangerous drugs being sold, as in the

1938 elixir sulfanilamide horror which painfully killed over 100 people and the infamous thalidomide disaster in the 1950s. As a result the Food and Drug Administration (FDA) was established, and saw its role firstly as protector of the public, without properly balancing its other role as provider of medication. This imbalance persisted until AIDS activists challenged it in the 1980s.

By mid-1989 there were sufficient victories to show that the battle was tipped in favour of the activists. Strong personalities and unholy coalitions (such as the one between Larry Kramer of ACT UP and Ellen Cooper of the FDA) had led eventually to groundbreaking reforms, such as the parallel track program for ddI, which gave ddI to over seven thousand people who were not improving on AZT therapy. But drugs were still not



1991 Health & Community Services D-Day protest. Peter Base lights candle.

reaching people. By then it became obvious that the problem wasn't confined to drugs not being approved fast enough; drugs were also not being *created* fast enough. A speedy drug approval system is no good unless there exist the drugs to approve. Stage 2 of the drug development process, the clinical trials system, was rife with bad science and worse management. In 10 years of AIDS, all the system had to show for its efforts was AZT. This time the unholy coalition was between ACTUP's Mark Harrington and research director Tony Fauci. Fauci eventually gave AIDS activists representation on decision-making committees within the AIDS Clinical

Trials Group, in the process causing a mutiny among the researchers.

By the way, this stage is where AIDS activism is at in Australia. For the most part, the battle to get drugs approved quickly has been won. ACTUP Sydney has been working for some time now to intervene at the clinical trials stage. Recently, the Australian AIDS clinical research director, Dr. David Cooper, and I had conversations about getting AIDS activists represented on decision-making committees. I trust there will be no mutiny here, the precedent having been set by the USA.

Reading *Against The Odds* made it clear to me that people with AIDS are

not going to be handed anything on a plate, and activists will have to intervene at *all* stages of drug development. And that's what worries me. The earlier in the process we intervene at, the more specialised the expertise we need. Any AIDS activist can say the drug approval process must be made faster. Few AIDS activists can look at a plasmid culture and say, "I think this compound can inhibit HIV replication." If that is the direction activism is heading in, we better get some training for our activists quick-smart.

Why should Australians read a book about AIDS drug development in the USA? Because chances are a new AIDS drug will not be discovered in Australia. We have no drug companies with the capacity to do basic research, and government basic science laboratories don't seem interested. Stage 1 work happens in countries like the USA, not Australia. Their science will always be ahead of ours and therefore so will their activist response. American activists have covered ground that we shall have to cover very soon. There are things we can learn from their experience. For example, in Australia we will soon have community-based trials (as opposed to government trials). US activists have been running trials since 1987. In 1989 two such trials provided data of such rigour that the FDA approved aerosolised pentamidine *solely* on that data.

As I finish writing this review I am assembling over 400 pages of a data package to submit to the Therapeutic Goods Administration to speed up their evaluation of ddC. A friend of mine in the US went to a lot of trouble and expense to get this package for me, and as I slave over this hot photocopier I think how absurd this is, because it's not my job to collect data. It's the TGA's job, whose many salaries we pay for without our taxes. I am getting angry all over again.

- Lyle Chan

What am I doing?

Rodney Junga:

Out of the Whirlwind...

AN INTERVIEW WITH RODNEY Junga leaves you feeling like you've just had a brush with a whirlwind - been whipped around the edges a bit and left breathless on the ground. This is no reflection on his personal style, which over the phone, is breezy rather than gale-force. It's because what he has to say about the effects of AIDS on Aboriginal people blows you away.

AIDS and Aborigines is mostly off the political agenda. But Rodney says he knows twenty-four Aboriginal people who have died of AIDS in the past three years - six of them since February. That was a shock to me because I realised that even though you may be personally affected by AIDS, the statistics are still faceless - the numbers are never broken down according to ethnicity. The consequence of that is invisibility. Even many Aboriginal communities haven't accepted that HIV is a problem for them, because the people who die of AIDS - or suicide for fear of it, as Rodney told me happens - may have left their communities because they're gay, or injecting drugs. Of those twenty-four people, Rodney says, most of their families don't know that they had AIDS.

Rodney Junga is one the HIV positive Aboriginal people who spoke to the National Aboriginal Conference in February (yes, the one where Fred Hollows came out of the woodwork with some reactionary ideas). But you're

sick to death of hearing about Fred Hollows. This story is about Rodney (who walked out during Hollows's speech. Rodney 'came out' to more than just a conference in February - he also came out to work colleagues at his new job, and to his community. Before the conference, only close friends and family knew his HIV status. Fortunately, after the Hollows episode the conference was unified by anger and Rodney went public in a supportive and politicised atmosphere. "We were all frightened and nervous about telling our status after Fred spoke", Rodney says. "But later we were happy, because, being on the last day, we had a big impact. We were able to say, 'this is the reality'."

For Rodney, coming out at the conference was in some ways the culmination of the long slow process of coming to terms with being gay and then with being HIV positive.

Rodney comes from South Australia originally - the Adelaide area and York Peninsula, where the Aboriginal people call themselves Nungas, not Koories. His tribes are Narunga and the Kurna. He left Adelaide at the age of fourteen and "found Sydney, where I continued a career as a sex worker. I did that and was an IDU until I was eighteen and decided to get an education. Last time I talked to the media that was their headline, 'twelve year

old junkie prostitute' - something like that." I promised not to make a big deal of it in *Talkabout*. Besides, if that's all the media thought was worth highlighting about Rodney's life, more fool them.

About this time AIDS turned up in Sydney. Rodney's initial response was to try and avoid it by getting married. Back in Adelaide, "I tried to become straight," he said. "Of course it didn't work. It was not long after I split up with my wife and decided I was gay I became positive. At that time people didn't know very much about AIDS, especially in Adelaide." He started travelling again. First Melbourne, then Sydney - to Tranby College. From Tranby he was involved in organising the first Aboriginal Solidarity group to go to Nicaragua, in 1988." I was the first out Aboriginal gay to go and work there, but I was still in the closet about HIV. It was a touchy subject in the Aboriginal community."

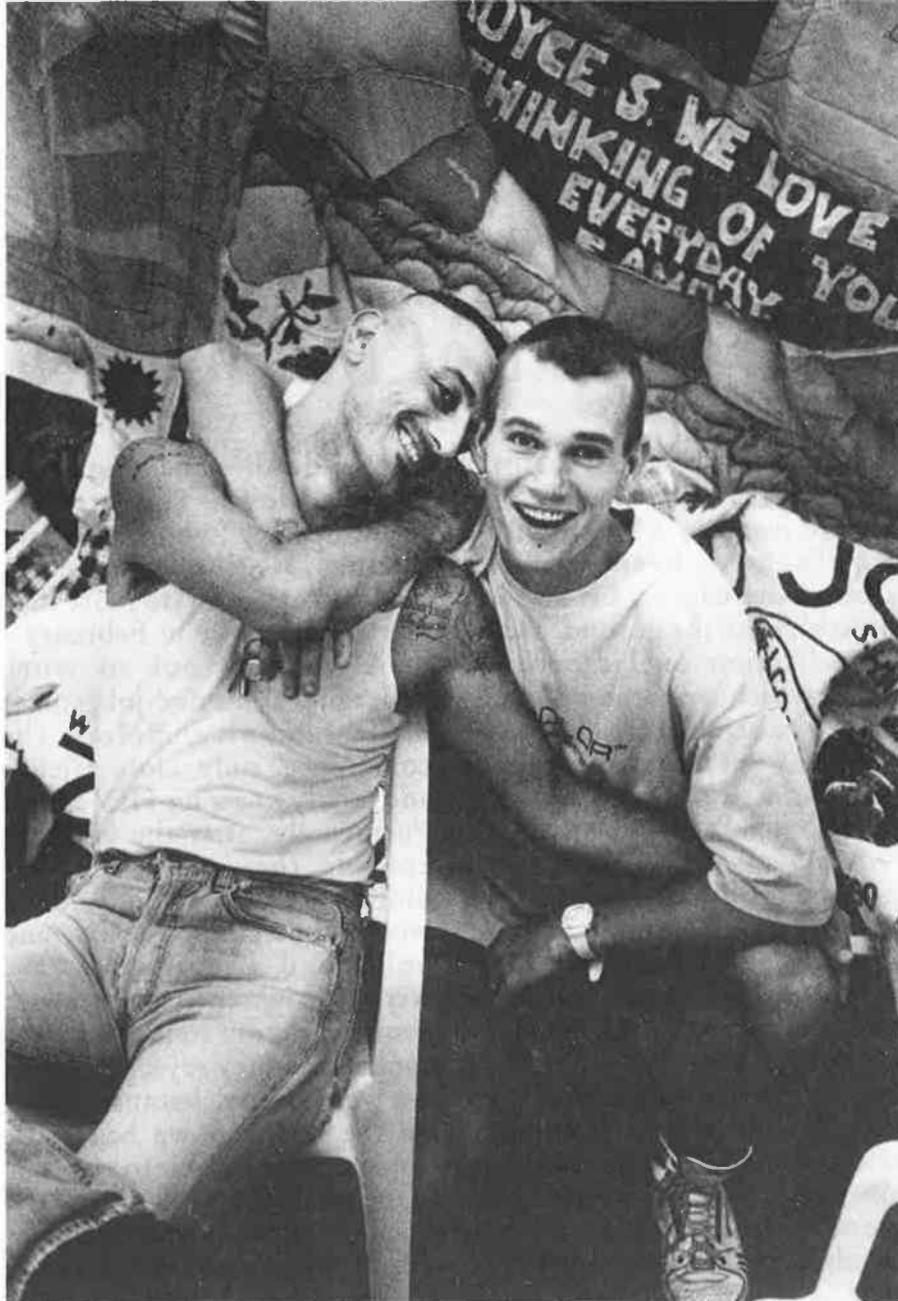
After Nicaragua, Mexico. This was where Rodney started having symptoms of HIV infection. He felt he needed to know more about what was happening to him, and headed for home. But, typical whirlwind, he didn't stay here for long.

A crucial experience for Rodney in coming to terms with HIV was getting to know other black people who were openly HIV positive. To do this he

decided to go first to America and then to London. After all, HIV positive Nungas were thin on the ground. He got a writer's grant to go to America in 1989, where he spent time in Los Angeles and San Francisco. The benefits of that time were meeting a lot of other HIV positive Black men and women, especially other writers, and getting a good look at the situation for positive people in the U.S. Not a pretty sight. Rodney was shocked at the poverty and the low living standards. "California is supposedly one of the best places in the U.S., but men would work as sex workers to get money to pay for AZT. The California laws are fucked. There are needle and syringe exchanges but only in the areas where people use crack - not needles!"

Despite being "spun out" by the U.S. trip, and a decline in health, Rodney's jet-setting continued. After a stay in Australia he went to the International Gay and Lesbian Conference in London in 1990. The conference offered another opportunity to connect with other HIV positive people. "I had been in denial about HIV", Rodney says, "not sharing that with people at all. I would have said that I was HIV negative, if anyone had asked me. I think that's related to my culture; being the oldest boy in the family is important in Aboriginal culture. At the conference in London I listened to all these black men and women talking about what it was like being out of the closet. I still feel the effects of that. As an indigenous person it had a big impact."

Back in Australia, Rodney started full-time work at Badlands. "I was the first Aboriginal there. It was bizarre for a lot of people, especially because I'm not your typical Aboriginal to look at. I look



Rodney Junga (left), with Warren Griffiths. PHOTO: LEON MORRIS.

more like Anwar Sadat, "I've got a hook nose, an olive complexion."

"Badlands is one of the most brilliant places. It's more than a half-way house, it may be the first time a lot of the people there have had a home. It was such a rewarding experience being a part of that team - men like Jacques Monroe and Blair Silverlock have taught me so much about being positive and getting on with things. It was also very hard. The first death while I was there was an Aboriginal man from South

Australia - I knew him as a teenager."

Around this time Rodney also trained as a volunteer facilitator with the HIV Support Project at ACON. Then he started to get sick again. It was time for a change. For all his work 'in' HIV and AIDS, Rodney believes, "it's no good how skilled you are when you're coming to terms with this disease. We had a joke in the support groups: 'yes, since I got the virus I've learned so much about myself and I'm thankful and now I'd like to give

it to someone else'."

"I was going to go to Nimbin and live on a pension and be a hippy but there was a job available in the Youth Sector Training Council in Adelaide. It was a perfect opportunity to go back to my language area and do some positive HIV education." This is the job he started a week before the conference in Alice Springs.

Being back in Adelaide is a new experience, because now everyone knows Rodney is HIV positive. It sounds like they're still working out the etiquette of how to relate to him - mostly with success.

"My support systems here are totally different to those in Sydney (where) it was all from other positive men and women, not just black but white, too. It was the best thing. Here it's family, friends, mostly HIV negative. The AIDS Council here is one of the best in the country, that I've seen, but most of the people here are HIV negative. South Australia is the only state where PLWAs are not a major political voice. There are not many out HIV positive men here."

"The best part of my new job is that people are slowly realising that people with HIV and AIDS don't want pity. They want to know how to care for us. When I need a break, people are beginning to understand."

The Nunga HIV/AIDS youth work project where Rodney now works is training people who work with young Aborigines. Rodney describes it as community education. "It brings in mothers and fathers, aunties and uncles. A lot of my work is going out to rural areas - like taking out a needle exchange worker from Redfern, showing Aboriginal people that AIDS isn't going to go away."

Although AIDS is relatively

new to Aboriginal people, its social symptoms - grief over multiple deaths, discrimination and stigma - are not. At thirty, Rodney is one of the older people in his Adelaide community. "There's so much death over here from murders, drugs, heroin. There aren't many Aboriginal people over twenty-five", he said. "We have had to deal with multiple deaths for two hundred years; now non-Aboriginal communities have to deal with that too. Hopefully, Aboriginal people will have access to what we're learning about that. That (knowledge) will help us survive.

"The rate of infection is supposed to be declining - but are they testing the right people? In Adelaide, people are scared to get tested because of the notification laws. GPs are testing without people's consent or knowledge, with no pre or post test counselling. And where's the counselling and education for HIV negative people? After ten years of AIDS I can honestly say this is the first year information is reaching some people. The national campaigns about HIV prevention are only just getting to people - and the government is looking at cutting funds!"

"I don't know how many Aboriginal people would be HIV positive, or maybe have suicided through fear without even being tested. The Aboriginal community still doesn't realise how close it is. Prevention is the only cure. We're all people living with AIDS. If you don't already know someone with it, soon you will. I live in fear that it's going to get worse before it gets better. Sydney now is like California was in 1989/90. It's visible in Sydney now. You can see it's here. It'll be the height of the disease in the next couple of years. I hope I'm one of the fortunate people who becomes a long-term survivor."

But the odds on that are not good if you're Aboriginal, and that's still Australia's shame.

At the time of WOMA Adelaide (Music Festival) in March this year, which was media-hyped as a celebration of cultural diversity, Rodney had a close encounter which showed him that police still have more of a problem with a person's aboriginality than they do with HIV. He was a passenger in a car after helping to dismantle a stall at the festival. There was a minor accident and the police arrived. They decided that Rodney was getting in their way and started beating him up, instead of helping him.

"They were hitting me and I started to bleed so I revealed my HIV status. They knocked me down, kicked me in the head and locked me in the van. They had me locked up for eleven hours before I could ring Aboriginal Legal Rights for assistance. That's against the ruling of the Commission into Black Deaths in Custody."

"The court case is still going on. I wanted them charged with assault. I could have gone to the media but I decided it would not be a good idea. It could jeopardise the project I'm working on. Police (in South Australia) still feel they have to know if you're HIV positive. Why, when it doesn't stop them bashing you up? Hopefully, their charges of hindering police and refusing to give my name will be dropped. They've said they'll drop the second if I'll plead guilty to the first - but I was just in an accident. I wasn't even driving the car."

I don't know how long Rodney's had HIV, but I'd say he's a long-term survivor already.

Jill Sergeant

Anguish in

BOHEMIA

CHAPTER 12

by M s A d a O.

The story so far: Rod the truck driver saved Nigel's life by blowing a big hole in his jeans. Robbie is very relieved because he has syphilis. He arrives home to find Brad and Nancy being carted off to hospital after having been attacked by a killer grand piano. Sitting on the kerb beside the shattered piano is its equally shattered owner, Leonard. Will everyone recover from their various ailments and tragedies? Read on to find out...

Nigel returns to disaster

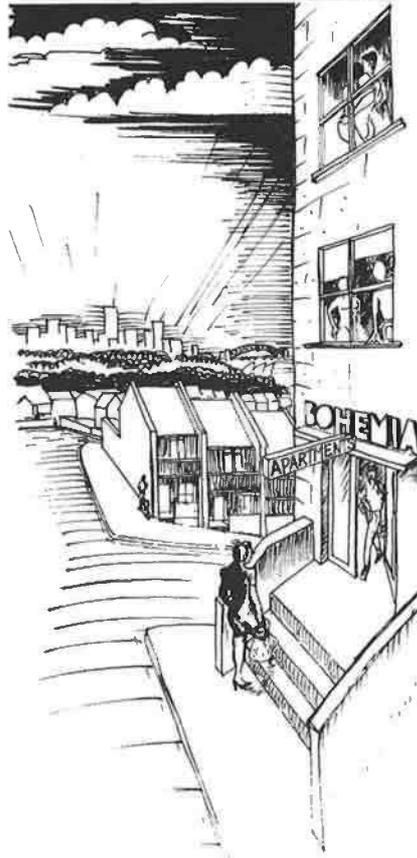
LEONARD, BOHEMIA APARTMENTS' newest resident, sat gloomily at his kitchen table. He had drawn piano keys on the formica with a felt-tip pen and was half-heartedly miming Rachmaninoff's C# Minor Prelude.

There was a knock at the door and he opened it to find a striking young man wearing a pair of highly distressed Levis, the crotch of which seemed to have been blown away with a shotgun.

"Ah, g'day, I'm Nigel from downstairs. Have you seen any of the people who live in this place?" asked the young man. "I just got back from interstate, and the place's completely deserted."

"They're all at the hospital I suspect," replied Leonard, wiping a tear from his eye. "There's been a disaster. Do come in."

Leonard related the day's incident to Nigel, who after comforting the distressed pianist, made for his own apartment for a shower and a change of clothes. In the taxi to King Elvis Hospital he tried to come to terms



with his life, but decided to leave it for later.

Beryl from Brewarrina

"EXCUSE ME YOUNG MAN, I THINK that's my seat."

"Are you sure? My ticket says 9D."

The woman in the floral sundress read her ticket once more.

"Oh, you're right. Silly me, I'm 9C, not D." She gazed forlornly at the young man. He looked up uneasily from the magazine he was

reading.

"Would you mind sitting next to the window?" she continued when she had regained his attention. "I find the window seat gives me a chill, and my doctor has advised me to avoid chills. Bad for my neuralgia. My water works -" and here she paused to give a knowing glance - "have also been given me dreadful problems lately so it's probably best that I sit in the aisle seat."

The boy looked at her aghast.

"Sure," he stuttered. He collected his few belongings and shuffled over to the window seat. The woman sat herself down next to him and sighed contentedly.

"It's a bit chilly on this bus, isn't it? I think I'll put my cardy on," she announced as the bus made its way through the drab outskirts of Brewarrina. The boy looked up from his magazine, smiled and resumed his reading.

"I'm Beryl Lewis," she announced several minutes later in a voice loud enough to ensure the rows in front and behind heard. Beryl thrust her hand forward and it was reluctantly accepted. She then searched through her bag and pulled out a Tupperware container loaded with lamingtons. She propelled it towards the young man who refused politely and went back to his book.

"Are you travelling all the way to Sydney?" an insistent Beryl inquired. The boy nodded without looking up from his book. "You're a shy little thing aren't you pet? Never mind, Aunty Beryl will fix that won't she?" She paused to bite her lamington. "Myself," she continued while her mouth was still full, thereby creating a snowstorm of coconut. "I'm off to visit my son.



The poor dear's gone and got himself squashed by a piano. Honestly pet, I didn't know whether to laugh or cry. 'That's our son' I said to Frank. Anyway, it's times like these a boy needs his mother. So I didn't waste a minute more. 'Menage-a-trois' I always say." Beryl smiled smugly. "That's French for 'a rolling stone saves nine'."

Beryl took another bite of her lamington as the boy, rapidly becoming lost underneath a growing mountain of coconut, watched in utter horror.

Sisters of Nursey

KING ELVIS HOSPITAL OVERLOOKED the rugged cliffs and wind-swept beaches of the southern coastal suburbs. It was said to be unlucky to have a sea view as it indicated that, in the estimation of your physician, you were not long for this world, and what little pleasure could be offered in your last days was not to be denied. But that was in the AIDS wards. Downstairs, in the emergency room Brad and Nancy had no views at all.

Robbie lurched from the taxi which had sped him to the hospital - hot on the tail of the ambulance carrying his sister and friend. Apart from a two minute stop at a takeaway food bar, the ambulance had not

eased up on either siren or speed. Robbie's taxi had followed in the slipstream, and he almost felt in need of emergency attention himself, as his guts were still somewhere back near Taylor Square.

The reception desk sister assured him the sister-in-charge would be out to give him the bad news soon. Robbie eyed the sister admiringly, for traditional nun's habit was rare in this modern age of K-mart cardigans and pantyhose. But here was a nursing nun who inspired confidence. After pacing the waiting room carpet pile down for a few minutes, Robbie decided to do something constructive. He wandered off in search of a public telephone. He called Wayne and blathered about syphilis, pianos and sisters. As usual, Wayne was supportive, promised to call his family for him, and be there as soon as he could. A little calmed, Robbie returned to the waiting room.

Sipping a cup of bad instant coffee, he waited until impatience finally overcame him. He sneaked passed the reception desk into the bowels of King Elvis' casualty. There was too much activity behind the scenes for anyone to notice him. Walking through one door Robbie interrupted a couple of men in white coats giving each other what seemed

to be a close physical examination. Just when he was about to give up searching, Robbie caught a familiar, strong, powdery scent despite the overpowering stench of hospital disinfectant.

"That's Torment!", Robbie said aloud. "Nancy's favourite perfume - she must be around here somewhere."

He peered through plastic doors into the emergency room. Dimly through the blur he made out the shapes of figures, swathed in bandages, with small hordes of sisters surrounding them. The machines by the trolleys had reassuring flashes and beeps, though strangely the beeps seemed to be playing the tune of Kum-ba-yah. Shaking this deranged thought from his mind, Robbie burst through the doors, and ran towards the bandaged figure that smelt of Torment most strongly.

"Nancy! Oh, Nancy!" Robbie sobbed.

The figure under the bandages groaned.

"Forget the cherries, go for the light," it murmured.

"Brad?" Robbie looked down perplexed, as the bandaged figure passed back into unconsciousness. Suddenly, Robbie was seized forcibly by two burly sisters, and

dragged back to the waiting room. Wayne had just arrived.

"Baby, honey, are you hurt?" Wayne asked, brushing the burly sisters aside. Robbie assured Wayne he was OK.

"G'day girls," the familiar voice of Nigel boomed across the waiting room, as he strode towards them.

"Nigel! When did you get back? Oh there's been a disaster - a piano's fallen on Nancy and Brad!" Robbie sputtered.

"Yeah, Leonard told me all about how they assaulted his baby grand from beneath. But how are they now?" Nigel asked.

"In the emergency room with a lot of burly nuns and machines beeping Kum-bah-yah," said Robbie frantically.

"Don't worry kid," said Nigel reassuringly. "Nancy is a real brick, and it'd take more than a grand piano to make a dent in that hard head of hers."

As they were speaking a tall,

strong faced sister approached with an air of authority and no nonsense.

"Are you Nancy's brother?" the sister-in-charge inquired. Oddly Robbie found the sister's gravelly voice strangely reassuring. "I'm Sister Mary. Your sister Nancy is in a very serious condition I'm afraid, and your friend Brad is still slipping in and out of a coma, muttering about cherries. Do you know what that's all about? Oh probably doesn't matter - deranged ravings really I expect."

"But will she live?" implored Robbie.

"Dingo willing," Sister Mary bowed her head towards an icon above the reception desk featuring a picture of a dingo and a scantily clad youth reclining before it. "But if I gave you any false hope about her chances it'd only be cruel when the inevitable happens. My boy, your sister has taken the full weight of a piano square on the shoulders you know."

"And how's that big queen, Brad?" asked Nigel.

"Oh, he'll pull through," Sister Mary's gravelly voice seemed a little terse. "Actually, he only sprained his arm a little. It seems Nancy pushed him clear just in time. She may have saved his life, but hers still hangs in the balance. We'd better keep Brad in for observation for a couple of days over at the Sacred Hard-on-Sea hospice. He's had a shock, and seems completely demented."

With that, Sister-in-charge Mary swept around and departed, the swish of starched cotton echoing behind.

The three of them stood in the waiting room, not knowing what to say next. Robbie sobbed quietly, under Wayne's strong arms.

"What did Sister mean by 'the inevitable'?" Robbie managed to gasp.

...TO BE CONTINUED

Biffy Mae's electric butter

One of the unpleasant side effects of chemotherapy is nausea. A helpful solution is described in this article, which has been shamelessly pirated from Diseased Pariah News and ruthlessly cut to fit this big space at the last minute.*

CHEMO IS BASICALLY A POISON, BUT a special kind of poison that is absorbed more readily the faster a cell is growing. Since cancer cells tend to grow explosively and out of control, they will theoretically suck up the poison first and die.

Unfortunately, there are a few other kinds of cells in your body that have a high growth rate, namely those in the stomach, intestines and hair. So your stomach, which normally renews itself once every four days, konks out and you feel

miserable (as if the new Telly Savalis look wasn't insult enough).

An anti-nausea remedy you might want to look into is an old but somewhat controversial solution: marijuana (THC). (Oh, wipe that shocked look off your face!) Aside from the counter barf effect, the appetite stimulating qualities of THC are renowned, just the thing to keep up your strength while taking bug killer.

As an alternative to smoking the stuff, Biffy Mae offers a humble alternative: the pot brownie. To avoid the kitty litter taste of cooking directly with leaf, sauté the marijuana in butter, on a low heat for about 15 minutes. Drain off the butter and reserve. When the dregs have cooled off, wring them out for any butter that's trapped inside.

Now remember, we're offering this purely as a medicinal alternative to classic anti-nausea therapy. Heaven knows, we at DPN wouldn't want to be accused of promoting prurient drug use, no no.

THC comes with a variety of side effects including immunosuppression, fatigue and photo-phobia, so discuss it with your doctor before you get into it.

DPN has included a classic brownie recipe, which unfortunately we don't have space to reprint. Maybe next month. Or phone in for a copy.

* DPN is published quarterly in California by a bunch of diseased pariahs

Home Front



AUGUST LAST YEAR BEGAN MY scariest and most frustrating experiences with HIV. Diarrhoea - liquid, constant and out of control. My appetite virtually disappeared, I had no energy, and, worst of all, my libido totally forsook me. I'd had a case of diarrhoea the year before, which had turned out to be a little amoeba living in my stomach - fairly easily treated.

The cause of this bout, however, was not so easily found. Stool sample - negative. Off to the specialist for an endoscopy - negative. Let's try a colonoscopy (vile procedure that it is) - negative. Wait a bit and try the endoscopy again - viola! Perseverance pays off in late March - microsporidia, a little bug that lives in the cells of the stomach lining (I believe) and has some sort of bizarre interest in stopping food absorption. By this stage I was down to 55kg.

The discovery of the microsporidia led to mild jubilation on my part, due mainly to a naive belief that once a doctor knows what's causing something, they can do something about it. Well, they could, sort of... "Yeah, well we can give you Flagyl for that". Ughh - Flagyl. What a fun drug - no drinking, food that tastes like aluminium and plummeting white cell counts. So I'm on 400mg three times a day. What the doctors neglected to tell me was that Flagyl works in only 20% of micro cases - not a very promising outlook. It worked for about a week.

A tantrum seemed to be in

order. It was worth it - through the special access scheme I was given Azithromycin, an experimental antibiotic. At the same time I started using nutritional supplements. I was putting on a kilogram a week, and soon started to actually enjoy eating real food again. If you've ever had serious loss of appetite you'll appreciate how this feels.

The funny thing was, throughout the whole episode, it had never really occurred to me how awful I felt, but I guess it was a case of serious denial. (Not knowing what was causing it certainly helped me to ignore my physical state.) I kept on going to work as a teacher (of adults, luckily) feeling nauseous and in constant fear of shitting my pants in the classroom. This denial continued until just before Mardi Gras when depression crashed in upon me. I had already arranged to have two weeks holiday after the party, and with the encouragement of a friend I rang my boss one night and simply said "Listen, I'm HIV positive, I'm in a bad way, I need two more weeks off." I would never have done that before. In fact, I felt very unhappy about telling anyone at work about my status, let alone my boss; but it was a last resort. As it turned out, she was great. I got the extra time, and used them to relax and think things over. It was about this time that the microsporidiosis was finally discovered.

Not working felt great, and the time off, plus discussions in a support group, convinced me that

I should stop work entirely. My doctors all supported the decision, probably because they realised better than I did how bad my condition was. Now I've got time to look after myself and do things that I want to do.

You're probably wondering what I was doing to cope with the diarrhoea for those eight months. Well, to tell you the truth, not a lot. I relied on ever increasing doses of Imodium to slow it down. I am (or was) a confirmed sceptic regarding "alternative" therapies, and even though people kept suggesting things like acupuncture, chinese herbs and ginger tea I never tried them while I was in the worst of it. I still find the idea of these treatments quite daunting, but were I to return to the state I was in, say three months ago, I would have no hesitation in giving them a go.

Reading this it may sound like I'm in perfect health and that everything is absolutely fabulous again. That's not quite true. The Azithromycin hasn't eradicated the micro - it's still there, but not as prolific, and unfortunately it hasn't been as effective for everyone who's tried it as it's been for me. I'm still on one or two Imodium a day, but joy oh joy doing, most of the time, solid shits (you'll never forget the feeling of solid shits hmmm, kinda catchy). My weight is now stable, but I still have the occasional bout of nausea and loss of appetite. Acidophilus powder and yoghurt seem to help, and yes, I'm drinking lots of ginger tea.

- Neil Sanderson

Fair Treatment



Towards a New Treatments Agenda for People with HIV/AIDS

TREATMENTS ISSUES HAVE GAINED A lot of prominence in the Australian response to AIDS over the last couple of years. Two years ago we believed we were sitting on the edge of the golden age of antivirals - that new, more effective drugs were on the way for HIV/AIDS. All that needed to happen was to substantially beef up our clinical trial mechanisms and speed up our drug approval processes to make sure that Australians could take advantage of new developments as soon as possible.

Unfortunately, while there were amazing successes at reforming the drug approval system and in giving more resources to clinical trials this has not yet resulted in the long promised golden age for people with HIV/AIDS.

There are reasons for this. The first is that we now understand that the mechanisms by which HIV does damage (ie, its pathogenesis) is a lot more complicated than we originally thought. Most attention has, until now, focussed on how HIV replicates inside cells, and how it ultimately kills the cells it infected (ie, direct killing). The existing drugs and those under development interfere with viral replication within cells. This is how the nucleoside analogues (AZT, ddI, ddC etc.) work (although they also work in ways we don't understand - the so called factor X's). The new drugs that are on the horizon - TAT gene inhibitors

and protease inhibitors - are also understood in terms of how they inhibit the viral replication process.

We now know that direct killing of cells by HIV is only a small part of the picture. Other mechanisms are going on and there is a whole body of emerging evidence that it is in combatting these other mechanisms that we may find far more effective therapies (and drugs). Unfortunately, people in community based organisations, people who give out research grants and people who define our research agenda including those who decide which trials Australia should participate in seem to be slow to appreciate the significance of what is occurring. It seems that a 'wait and see' attitude is being adopted because the feeling is that we don't know enough yet. We probably don't but I think we know enough to see that this is the future and unless we start planning now to take advantage of these new therapies we will have missed the boat. My fear is that it is not calculated 'wait and see', but 'head in the sand' - an unwillingness to be truly open-minded about available evidence and a desire to hang on to existing beliefs.

I am not suggesting that we need to throw the baby out with the bath water here. Existing drugs such as combination nucleoside therapies are showing wonderful results. Protease inhibitors and TAT gene inhibitors may still be

very useful additions. However, drugs which only interfere with viral replication inside cells are ultimately not likely to be THE answer. They are likely to be used in combination with other therapies.

My second reason for thinking we're having problems is that I don't think there are appropriate and effective mechanisms for consumer input into trial design. While some mechanisms are in place and while the head of the National Centre in HIV Epidemiology and Clinical Research, Dr David Cooper, is very available to groups like ACON and ACT UP, I'm not sure that effective consumer input into trial design and in particular trial initiation exist. This may be the result of the community based movement not taking advantage of, or using properly, the mechanisms that do exist or it may be that the mechanisms themselves could be improved.

From what I can discern of the national trials strategy I perceive the following problem areas :-

i) The Community HIV/AIDS Trial Network (CHATN) has been very slow to get started. CHATN was designed to conduct HIV/AIDS trials through 'community' settings (ie, general practice). Given Australia's HIV population (ie, mostly well) and the drug development process expanding back into the 'well' population, this need is obvious.

ii) While our successes in anti-viral trials are world renowned we have a growing body of people who are candidates for opportunistic illness trials. The lack of priorities (as measured by what is happening and not by intent) given to opportunistic infection trials and other non anti-retroviral pharmaceutical trials such as post-infection vaccine trials and other non-pharmaceutical therapies need to be re-examined.

iii) Urgent attention needs to be given to resolving on-going legal / ethical problems associated with trial initiation (ie, the CTN scheme).

iv) The role and function of Clinical Treatments And Trials Advisory Committee (CTTAC) - the body charged with developing and promulgating a national HIV/AIDS treatments & trialing strategy

If we define the drug/therapy development process as having four main components - discovery, trialing, approval and payment - then in HIV/AIDS we have tackled approvals and have begun on trialing (but we still have a long way to go). An emerging problem is that of who is going to pay for these expensive drugs and therapies. Ultimately approval is a waste of time if people can still not get access to, or afford treatments. Payments for pharmaceuticals and expensive therapies is a huge political issue which applies to the whole health system. It has been in the 'too hard' basket and the 'bureaucratic shuffle' for too long. Unless resolved, it is going to become an issue that will dominate the health and AIDS agendas in the next couple of years.

The fourth area - 'discovery' -



PHOTO: JAMIE DUNBAR

that of identifying potential new drugs or therapies is an area that is beyond my scope and expertise. Currently, deciding exactly what drug or therapy goes on to be further developed occurs, mostly, overseas and is influenced by a whole set of factors including profit and politics. For activists it is an area that can't be ignored but one in which, as yet, we have few skills or knowledge. In Australia, we tend to believe that this sort of hard-core basic science belongs overseas despite rhetoric about 'clever' countries. We could give more support to CSIRO. We could also give tax incentives for drugs developed here similar to the orphan drug laws in the United States. I have often seen potential agents discovered here but most of the development seems to occur overseas.

While much has been gained in the last couple of years for people with HIV/AIDS in terms of drug approvals, access, education and information it is perhaps time to take stock and to define an agenda for 1992 and beyond. For me that agenda includes:

1. Recognition of the new understanding of HIV pathogenesis by increased funding

of basic research and new therapies in this area.

2. Increased priorities in the national trials strategies with regard to:

post infection vaccines
new therapies which take account of new models of pathogenesis

opportunistic illnesses
immune restoration

3. CHATN to be established and operational as soon as possible.

4. The legal impediments that are slowing trial initiation to be resolved.

5. New and improved consultative and input mechanisms for people with HIV/AIDS into research and trial design.

6. Clear and defined policy that ensures equity and access to HIV/AIDS treatments for all Australians.

This article has only briefly canvassed some of the issues. It is signalling to doctors, the government and community based organisations that HIV/AIDS treatment issues remain an issue needing further work.

-- Ross Duffin

Doctor, Doctor



I MENTIONED LAST MONTH THAT I was going to talk about the Delta trial that is currently enrolling participants in Sydney. There were some concerns about aspects of the trial. For further information on these trials please see the article in *HIV Herald*, May/June 1992.

In the mostly-unknown territory of AIDS/HIV treatment there are certainly no perfect answers. And until there is a total solution it seems that informed trial and error is a way of finding effective treatment strategies. The alternative treatment movement (for example Chinese herbs or homoeopathy) has created a credible and sometimes useful menu of choices for people to try - often in addition to and sometimes in place of conventional medical treatments.

And now for the motherhood statement: Doctors genuinely care what happens to their patients. But one thing that very few doctors want to do is rock the medical establishment boat.

Doctors will seldom initiate new treatments. In the conventional medical system it is the drug companies which, motivated by sole patent rights as well as profit, set the stage for trying out new drugs.

Therefore doctors, while perhaps not antagonistic to alternative treatments, will often not consider that they are an adjunct to the more effective or wholistic treatment of people with HIV or AIDS.

Anyone considering using unapproved drugs or alternative treatment should ideally 'suss' out

the feelings of their doctor on the issue. A lot of this depends on your willingness and ability to talk to your doctor.

If your doctor is vaguely sympathetic or even objectively neutral, you should get his/her advice, given that he/she probably knows a lot more about your health than any other health professional.

Obviously, from your doctor's point of view, you are, if involved in other treatment options, 'playing around'. The doctor can justly feel that he/she cannot be held responsible for these other options. How could your doctor be expected to know what the Chinese herbs that you are taking are doing to your body?

If you have decided to play the field and expand your treatment options, you could take the following approach. Assuming that you have a sympathetic doctor, initiate a discussion about these alternatives.

If you ask, "should I use this alternative drug/treatment?" your doctor is almost constrained to say no, because of his/her belief in the orthodoxy of the western medical system and because of ignorance of the consequences of the particular treatment. If you say, instead, that you plan to do such and such an alternative treatment, then an informed and sympathetic doctor can discuss the pros and cons and offer advice on how to do it safely with his/her monitoring - or explain why you should not do it at all.

This serves two purposes. Firstly, it gives your doctor a full

awareness of all the factors in your treatment. (It works the other way too; you should tell your alternative health practitioner exactly what your situation and current medical treatments are.) Secondly, and most importantly, it gives your doctor extra information about what may or may not be working in the long term management of the infection. Consequently your doctor will be able to pass on this knowledge to others who are considering alternative treatment options.

And so we come back to the point I made at the beginning. We are all (including doctors) in mostly-unknown territory. The more information that can be gleaned from *any* source about what is effective in managing HIV and AIDS, the better for everyone.

Now we continue with our series from *AIDS Treatment News* about dealing with your doctor.

Managing the time with your doctor

THERE ALMOST NEVER SEEMS TO BE enough time in any health care setting, whether private, clinic or public hospital, although some of these settings are certainly worse than others. This problem will probably never be solved, but it may be helpful to think about a few of the reasons that time always seems unnecessarily limited.

In some settings, the doctor essentially has no control over the length of each appointment. You will often find yourself waiting for long periods of time, and feeling very frustrated. Keep in mind,

however, that you are most likely waiting because the doctor spent more than the allotted time with the other patients. The doctor in this situation is constantly battling conflicting needs: the need to stay on schedule so you don't have to wait too long and the need to spend 'extra' time with patients who need medical or emotional attention.

A simple solution may seem to be to schedule fewer patients each day. While it is certainly true that some doctors have large practices for financial reasons, more often the physician is again confronted with conflicting needs: to take patients who need a doctor (good HIV doctors are in high demand), to see patients on short notice (how often do you feel frustrated by having to wait days or weeks for an appointment?), and to schedule sufficient time with each patient. In this difficult equation, appointment time is often the loser.

In spite of this pessimistic assessment of time, some doctors and offices are better than others about staying on schedule and spending sufficient time with each patient for the patient to feel that his or her needs are being met. When possible, talking to other patients who see a particular doctor is probably the best way to determine how much of a problem scheduling will be.

A final comment on time: Often, a fair amount of time is spent thinking about each patient when the patient is not there. A responsible doctor reviews the chart before going in to see the patient, to refresh his or her memory about that patient's history, and then spends some time thinking about what the symptoms mean and how to approach them when they write the chart note after the patient leaves.

This fact may not make you feel any better cared for when the doctor seems to be rushed and not giving you the attention you want

and need, but it's good to keep it in mind when you are assessing the care you are receiving. Is the care good, even if you don't feel like you are getting enough time? If so, the doctor is probably doing a good job 'behind your back'. If not, you may need to talk to your doctor about the time issue and other reasons you may not be getting the care you need.

Next month this series will

finish with some ideas on 'How do doctors think?' and also 'Following up'.

Till then, ciao for now
- Peter Hornby

P.S. If any HIV/AIDS doctors would like to address the issues and concerns raised in this column then I would certainly like to hear from you. If requested, your anonymity will be protected.

Talking Drum

TALKING DRUM CONTINUES THIS month, with an answer to the question of mouth ulcers (*Talkabout*, July).

MELISSA,

In response to your question regarding mouth ulcers, I've been involved in oncology for a long time and most of the patients I've dealt with have stomatitis (inflammation of the oral cavity or pharynx secondary to chemotherapy).

Several measures have been useful, whether the ulcers have been caused by an infective process or as a result of therapy.

The major factor is good oral hygiene. The most simple and cheap way to make a good mouthwash is 1/2 teaspoon salt in 1 litre boiling water, let cool and rinse and gargle to your heart's content.

Symptomatic measures to relieve the pain associated with ulcerations are readily available from chemists. Cepacaine mouthwash has antiseptic and analgesic properties. It acts topically by virtually inducing a numbness or decreased sensitivity in the mouth.

Direct application of Bonjela gel

has also been of use. Xylocaine Viscous is a great reliever of pain. It is a thick, reddish substance which can easily be diluted in a little water and gargled. A simple analgesic like Paracetamol can also be of help. Soluble aspirin as a gargle has worked for some people; you can also swallow it after you've gargled.

Of course, avoidance of foods or drinks which aggravate the pain associated with mouth ulcers can also help. Acidic fruit juices, curries, oranges all tantalize the taste buds, but add new dimensions to the experience of pain.

It also goes without saying that you should consult your practitioner, whether medical or dental, for assessment and isolation of the cause. Too much smoking damages the mucosa of the mouth and aids erosion. Herpes could be the cause too. So, assessment of the cause is vital.

Michael Gibbons R.N.

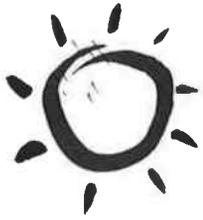
If you have any questions about HIV/AIDS matters that you would like answered, drop us a line.

**Talkabout, PO Box 1359
Darlinghurst 2010,
Phone 283 3220.**

What's Goin' On



HIV living



daytime



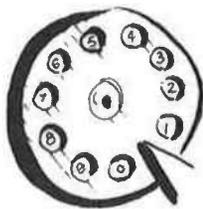
support groups



starting soon



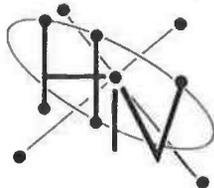
**talk to
peter or russell**



(02) 283 2453

or (02) 283 3222

TTY (02) 283 2088



**SUPPORT
PROJECT**

**Are you
a gay man
who is currently
participating, or has
participated in an HIV
clinical trial?**

If so, we'd be interested in talking to you about your experiences. It takes about 30 minutes and confidentiality is assured.

The study is concerned with the effects of trial anti-HIV agents on an individual's quality of life.

If you are interested in participating in this study, call Lorna Ryan, 332 1090 ext 290 (Monday -Friday 10am - 6pm) for further details.

**National Centre for
HIV Social Research**

**SERVICING THE
WESTERN SUBURBS**

*The Kendall
Centre*

**AIDS information and
support services
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- Condoms •
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- Support groups •

A unit of the Western Sydney Area
Health Service

26 Kendall St Harris Park 2150

Tel. 893 9522 Mobile 018 251

888 Fax. 891 2087

RED CROSS

Cosmetic Care Specialist Service

A service that trains people with Kaposi's Sarcoma (KS) to apply covering makeup is available at Ankali Cottage. A trained consultant assists the individual to choose the correct skin tone, and in correct application and removal of the makeup.

Use of makeup can assist individuals in raising their self-esteem.

The service is free.

APPOINTMENTS
are necessary.

Telephone (02) 332 1090
- ask for Ankali Cottage.

Enquiries can be made
by calling the *Cosmetic
Care Coordinator* at
the Red Cross on
(02) 229 4296.

LET'S DO LUNCH



The *Talkabout* editorial group meets twice a month for lunch. While we're at it, we talk about — *Talkabout*.

The editorial group discusses what should go into *Talkabout* each month. Some of us write articles or interview people, some of us contribute ideas and opinions. You don't have to be a brilliant writer or A grade journalist to get involved.

The next meetings will be:
Thursday, August 6 and
Thursday, August 27.

Meet at the PLWHA office at 12.45, 2nd floor, 188 Goulburn St Darlinghurst. Call Jill on 283 3220 if you have any questions.

S I L K R O A D

A social and support group for Asian gay and bisexual men which meets every Friday.

Activities include workshops, discussions, social activities, etc.

More information available from
Arnel on (02) 283 3222

Join ACON's Meditation group

ground floor
AIDS Council of NSW
188 Goulburn st, Darlinghurst

ALL WELCOME

Open to all people living with HIV/AIDS, their friends, supporters, carers, health workers etc.

Meditation can be useful as a means to reduce stress, energise the body and increase clear thinking

Instruction and assistance in how to meditate is available to newcomers

Tuesday mornings 9am - 10pm

Thursday evenings 6pm - 7pm

Just turn up, or ring David (02)358 1318

HANDS ON

• Massage and Reiki for PLWHAs

• Training of volunteer masseurs

Call Richard
660 6392

Contact List



GENERAL

AIDS Coalition to Unleash Power (ACT UP) A diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis.

Phone the Info Line 281 0362. PO Box A1242, Sydney South 2000.

AIDS Council of NSW (ACON) Provides services in education, welfare, support and advocacy in relation to HIV/AIDS to the gay and general community.

AIDS Resource Centre

188 Goulburn St, Darlinghurst 2010. 283 3222, fax 283 2199.

ACON Hunter PO Box 1081, Newcastle 2300. (049) 29 3464.

ACON Illawarra PO Box 1073, Wollongong 2902. (042) 76 2399.

ACON Mid-North Coast PO Box 990, Coffs Harbour 2450. (066) 514 056.

ACON North Coast PO Box 63, Sth Lismore 2480. (066) 22 1555.

ACON's Rural Project Telephone service for men who have sex with men. Info on HIV health services, gay networks/advocacy. Encourages the adoption & maintenance of safe sex practices in country NSW. Call Nik or John 008 80 2612 (free call). PO Box 350 Darlinghurst 2010.

AIDS Trust of Australia A non-government national fundraising body which raises money for research, care and education related to HIV/AIDS. PO Box 1272, Darlinghurst 2010. 211 2044.

Australian Federation of AIDS Organisations (AFAO) Umbrella organisation for Australian state and territory AIDS Councils. (06) 247 3411.

Central Coast Services Sexual health service, support groups, positive support network. For info call Peter (043) 23 7115 or Paul (043) 20 3399.

Deaf Community AIDS Project Call Colin Allen at ACON 283 3222 or (TTY only) 283 2088.

Euthanasia Voluntary Euthanasia Society of NSW Inc. PO Box 25 Broadway, 2007. 212 4782.

Fun and Esteem Workshops and drop-in groups for gay or bisexual men under the age of 26. Meets in Darlinghurst and Parramatta. The groups are a chance to talk about everything from safe sex to coming out. Social and fun. For more information call Aldo or Brent 283 2599.

Kids With AIDS (KWAIDS) and Parents of KWAIDS. Inquiries c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772. Donations c/- AIDS Trust, 211 2044.

Metropolitan Community Church (MCC) International gay church. 638 3298.

National Centre in HIV Epidemiology & Clinical Research Federal research centre conducting trials for AIDS treatments and other AIDS related research. 332 4648.

National People Living With AIDS Coalition (NPLWAC) GPO Box 164, Canberra ACT 2601. Call (06) 257 4985.

New England Needle Exchange Program Fits, swabs, water, condoms, lube, information and education. For locations of outlets and outreach services call (067)66 2626 message, (018)66 8382 mobile.

NSW Anti-Discrimination Board Takes complaints of AIDS related discrimination and attempts to resolve them by a confidential process of reconciliation. Currently employs a full time AIDS Project officer. Sydney 318 5400.

Newcastle (049) 26 4300. Wollongong (042) 26 8190.

NSW Users and AIDS Association (NUAA) Community/peer based organisation providing advocacy, support and referral for injecting drug users and their friends. Needle exchange services also available. Free

forums/information nights 3rd Monday each month at 6pm. 369 3455.

Quilt Project Memorial project for those who have died of AIDS, consisting of fabric panels completed by friends, lovers & family of those to be remembered. 283 3222.

Sex Workers' Outreach Project (SWOP) 391 Riley St, Surry Hills. 212 2600.

Social Workers in AIDS (SWAIDS) A special interest group for social workers working with people with HIV/AIDS. Contact the secretary, Lib Edmonds, C/- Kirketon Road Centre, PO Box 22 Kings Cross, 2011 or the chairperson, Grahame Colditz, C/- Prince Henry Hospital, 694 5721.

South East Region HIV/AIDS Unit HIV/AIDS support, needle and syringe exchange and HIV education. For more information contact (048) 21 8111.

Sydney South West Needle Exchange For access and locations call 601 2333 or Mobile 018 25 1920.

DAY CENTRES

Blue Mountains PLWA Support Centre Wednesdays 11am - 3pm (lunch). Fridays 6.30 - 10.30pm (dinner).

For further information call the Centre on (047) 82 2119 or Dennis (047)88 1110.

Central Coast (Konnexions) HIV+ Drop-In Centre, 11am-3pm Mondays at the old stone building, Anglican grounds 3 Mann St Gosford. Inquiries Pauline (043) 20 2241.

Newcastle (Karumah) Upstairs, 101 Scott St Newcastle, opposite Newcastle Railway Station. Every Thursday from 11am. Contact John (049) 62 1140 or ACON Hunter branch (049) 29 3464.

Sydney (Maitraya) Daytime recreation/relaxation centre for people with AIDS. Lunch Tues, Wed, Fri. (free or donation). Massage also available.

Some group meetings. 396 Bourke St Surry Hills. Inquiries (incl. membership) 361 0893. Client's phone 360 9896.

CLINICS & HOSPITALS

Albion Street AIDS Centre (Sydney hospital AIDS Centre). Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. 332 1090.

Haemophilia Unit Royal Prince Alfred Hospital, 516 8902.

John Hunter Hospital (Clinical Immunology Ward) Lookout Rd, New Lambton, Newcastle. (049) 21 4766.

Kirketon Road Centre Community based primary health care facility of Sydney Hospital. Nursing, medical services, counselling, 9am - 8pm, Mon-Fri. Social welfare service, needle & syringe exchange 9am - midnight Mon - Fri. Cnr William St & Kirketon Rd, Kings Cross. 360 2766.

Lismore Sexual Health/AIDS Service A free, confidential service for all STD and AIDS testing and treatment. For further information or appointment (066) 23 1495.

Prince Henry (Special Care Unit) Anzac Parade, Little Bay. 694 5237 or 661 0111

Prince of Wales (Paediatric AIDS Unit) High St Randwick. 399 0111.

Royal North Shore Pacific Highway, St Leonards. 438 7414/7415.

Royal Prince Alfred (AIDS Ward) Missenden Rd, Camperdown. 516 6437.

Sacred Heart Hospice A palliative care facility. 170 Darlinghurst Rd, Darlinghurst. 361 9444.

St George Belgrave St Kogarah. Inpatient/outpatient & day treatment centres and STD clinic. Call 350 2742/43.

St Vincent's (17th Floor South AIDS Ward) Victoria St, Darlinghurst. 361 2337.

Sydney Sexual Health Centre Sydney Hospital, Macquarie St, Sydney. Appointments 223 7066.

Transfusion related AIDS (TRAIDS) Unit: For people with medically acquired HIV/AIDS. Crisis/long term counselling

and welfare support to clients and their families throughout NSW. TRAIDS is based at Parramatta Hospital. Contact Pam or Claire 843 3111 ext.343. **Red Cross BTS:** Contact Jenny 262 1764. **Westmead Centre** (Westmead and Parramatta Hospitals) Westmead 633 6333. Parramatta 843 3111.

EMOTIONAL SUPPORT

Ankali Emotional support to PLWAs, their partners, family and friends. volunteers are trained to provide one-to-one non-judgemental and confidential support. Ankali is an Aboriginal word for friend. 332 1090.

Bathurst AIDS Support Group Meets Tuesdays 7-9pm at the Women's Health Centre, 20 William St. Call Vi (063) 31 4133.

Bega Valley HIV/AIDS Volunteer Carer Group Provides emotional and practical support to PLWAs, their family & friends living in the Bega Valley area. Call Ann Young (064) 92 9120 or Victor Tawil (048) 21 8111.

Civil Rehabilitation Committee Family Support Centre. HIV education and support to families of ex-prisoners and ex-offenders.

Call Pam Simpson 902)289 2670.

Friends & Partners of People With AIDS A peer support group for friends and partners of PLWAs. 7pm, 1st and 3rd Mondays in the month at Maitraya Day Centre, 396 Bourke St Surry Hills. Inquiries Gary 369 2731.

HIV Living Support Groups For HIV+ people. Call HIV support officers 283 3222/2453.

Hunter Area HIV Support/Action group 6.30pm, 4th Wednesday every month at ACON, level 1, Bolton St Newcastle. Inquiries call ACON (049)29 3464.

Karuna Blue Mountains Emotional support for people with HIV/AIDS, their partners, family and friends. Call Ann (047)82 2120.

Newcastle Gay Friendship Network Peer support, workshops and activities for gay men under 26. Call ACON Hunter branch, (049) 29 3464.

North Coast Positive Time Group A support and social group for PLWAs

in the North Coast region. Contact ACON North coast (066) 22 1555.

Parent's FLAG Parents and friends of lesbians and gays. Meets monthly at the GLCS, 197 Albion St Surry Hills. Call Heather, 899 1101, Marie 360 3250.

Parent's Group (and relatives) A support group for the parents or relatives of PLWAs. Every 2nd Wednesday at 12.30. 5th floor, Notre Dame Bldg. Burton St Darlinghurst. Call Linda Barr 339 111 (page 248) or Marie Pettitt (page 256) to indicate attendance.

Partner's Group A support group mainly for partners of people who are in/outpatients at St Vincent's. every 2nd Tuesday, 6-8pm. Please phone Chris Connole 339 1111 (page 345) or Lesley Goulburn (page (255) if you're interested in attending.

Positive Women Individual or group support for and by HIV/AIDS positive women. Non-judgemental and completely confidential. Contact via Women and AIDS Project Officer or Women's HIV Support Officer at ACON, 283 3222, TTY for the Deaf 283 2088. PO Box 350 Darlinghurst 2010.

Positive Young Men A support group for positive gay men under the age of 26. Groups run for 6-10 weeks at a time. Groups are run by Fun and Esteem and the HIV Support Project. For information phone Aldo or Brent 283 2599 or HIV Support 283 2453.

Quest for Life Foundation Emotional support and education for people with life threatening diseases, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. 906 3112.

Shoalhaven HIV Support group Meets first and third Tuesdays in the month from 6pm to 7pm. This is a peer support group facilitated by an HIV+ volunteer. It is completely confidential. Call (044) 23 9353.

Sydney West Group: a Parramatta based support group. Pip Bowden 635 4595.

PRACTICAL HELP

ACON Housing Project offers help with accessing priority public housing, transfer advice, homelessness, private rented housing/share housing, housing

Service Update

discrimination and harassment. The Housing Project Officer is available by appointment, call 283 3222, ext. 246. 188 Goulburn St, Darlinghurst. PO Box 350, Darlinghurst, 2010.

Badlands Residential harm reduction service providing a safe, non-coercive space for up to ten people at a time, who are at high risk of HIV transmission or may be HIV+. Residents are mainly injecting drug users and/or may be sex workers. 382 - 384 Bourke St, Surry Hills 2010. 360 7661.

Bega Valley HIV/AIDS Volunteer Carer Group Provides emotional and practical support to PLWHA, their family & friends living in the Bega Valley area. Call Ann Young (064) 92 9120 or Victor Tawil (048) 21 8111.

Bobby Goldsmith Foundation A community based, registered charity providing direct financial aid to people with advanced HIV/AIDS to help meet rental, telephone, electrical, gas and some vitamin costs and child care assistance to approved clients. 4th floor, 376 Victoria St, Darlinghurst, 360 9755.

Central Coast Positive Support Network (PSN) Trained volunteers providing practical home/personal care for people with AIDS. Inquiries Peter (043) 23 71 15 or Paul (043) 20 3399.

Community Support Network (CSN) Trained volunteers providing practical home/personal care for people with AIDS. 283 3222.

CSN Blue Mountains hands on practical help for people with HIV/AIDS. Call Robert (047) 87 7984.

CSN Newcastle Call Rosemary Bristow, ACON Hunter Branch. (049) 29 3464.

CSN Wollongong Call David Mendaue, (042) 76 2399.

Legal Project (AFAO) Legal advice and advocacy on HIV/AIDS related problems.

Call Michael Alexander 283 3222.

North Coast- Wollumbin CARES Community AIDS Resources and Support. Call Simon (075) 36 8842.

Tiffany's Transport Service For PLWAs (in the Sydney area.) 360 2043.

IS YOUR LISTING CORRECT?

Please let us know of any relevant contacts for the next issue

Albion Street Centre

• *Diagnostic Procedures for Opportunistic Infections*

SERVICES INCLUDE INDUCED Sputum Collection, Lumbar Puncture, and Tissue Biopsy. Referrals should be directed to clinic nurse or Day Treatment Registrar.

• *Specialised Treatments*

ZIDOVUDINE AND DIDANOSINE dispensing. Intravenous infusions available, including Ganciclovir, Pentamidine (IV and nebulised), Amphotericin, Antibiotics, and Chemotherapy for malignancy. Referrals should be directed to clinic nurse or Day Treatment Registrar.

• *Counselling*

THE STAFF OF THE COUNSELLING unit are Psychologists who provide a wide range of clinical services to clients. The many psychosocial issues faced by HIV infected clients at all stages of their illness contribute significantly to depression, anxiety and distress which may be appropriately addressed by referral for assessment and therapy. Referrals may be made for psychological assessment (and follow-up), social assessment (and follow-up), crisis counselling, medium to long-term counselling (psychotherapy). Clients need to make an appointment with clinic reception.

ASC Speciality Clinics

• *Ophthalmology*

AVAILABLE EVERY MONDAY morning from 8.30 to 10.30am. Patients may be in clinic for approximately 1 hour. Referrals can be made for 3/12 screening of patients with CD4 < 200 for early detection of CMV retinitis. Each visit involves visual acuity evaluation, pupil dilation, funduscopy, and CMV serology (where relevant). Evaluation of any eye symptoms in immunosuppressed patients can be undertaken, but at present, no slit lamp facilities are on site, therefore referral to Hospital Eye Clinics may be preferable in most situations involving symptomatic patients.

• *Dermatology*

AVAILABLE 1ST AND 3RD FRIDAYS of each month, from 10.00 to 11.30am (with two concurrent clinics). Referrals can be made

for all dermatological conditions requiring assessment, with or without biopsies, and dermatological opinion regarding management.

• *Oncology*

EVERY WEDNESDAY AFTERNOON from 2.00 to 5.00pm. Referrals can be made for assessment of patients with symptoms/signs suggestive of malignancy, ongoing chemotherapy for patients diagnosed with HIV-related malignancy.

• *Rheumatology*

EVERY WEDNESDAY MORNING from 9.00am to 12.30pm. Referrals can be made for assessment of any rheumatological / CT tissue disorder, assessment of patients for diagnosis and management of Sjögrens Syndrome or related condition.

JOIN US IN THE FIGHT AGAINST AIDS. SUBSCRIBE NOW.

PLWHA Inc. (NSW) is part of a world-wide movement to empower people with HIV infection, their friends, supporters, family and lovers to live full, creative and meaningful lives free from fear, ignorance and prejudice.

Help yourself and others affected by HIV to create a positive, friendly and supportive environment in which we can all live with HIV & AIDS — join PLWHA.

FIRST NAME _____ LAST NAME _____

POSTAL ADDRESS _____

_____ POSTCODE _____

PHONE _____ (W) _____ (H) _____

I wish to apply for membership of PLWHA Inc. (NSW)

I wish to subscribe to *Talkabout*

I wish to make a donation of: \$ _____

I enclose a cheque/money order for \$ _____

In the interests of your confidentiality

I agree to have other members know my name and address Yes No

I am publicly open about my membership Yes No

Annual rates are

Membership \$2

Subscription donation to *Talkabout* (optional for people receiving benefits)

Individual \$10

Organisation (up to 4 copies) \$20

(up to 10 copies) \$30

Please specify number of copies _____

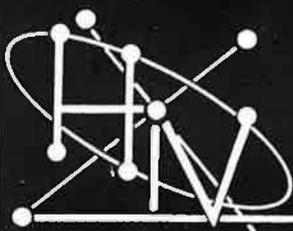
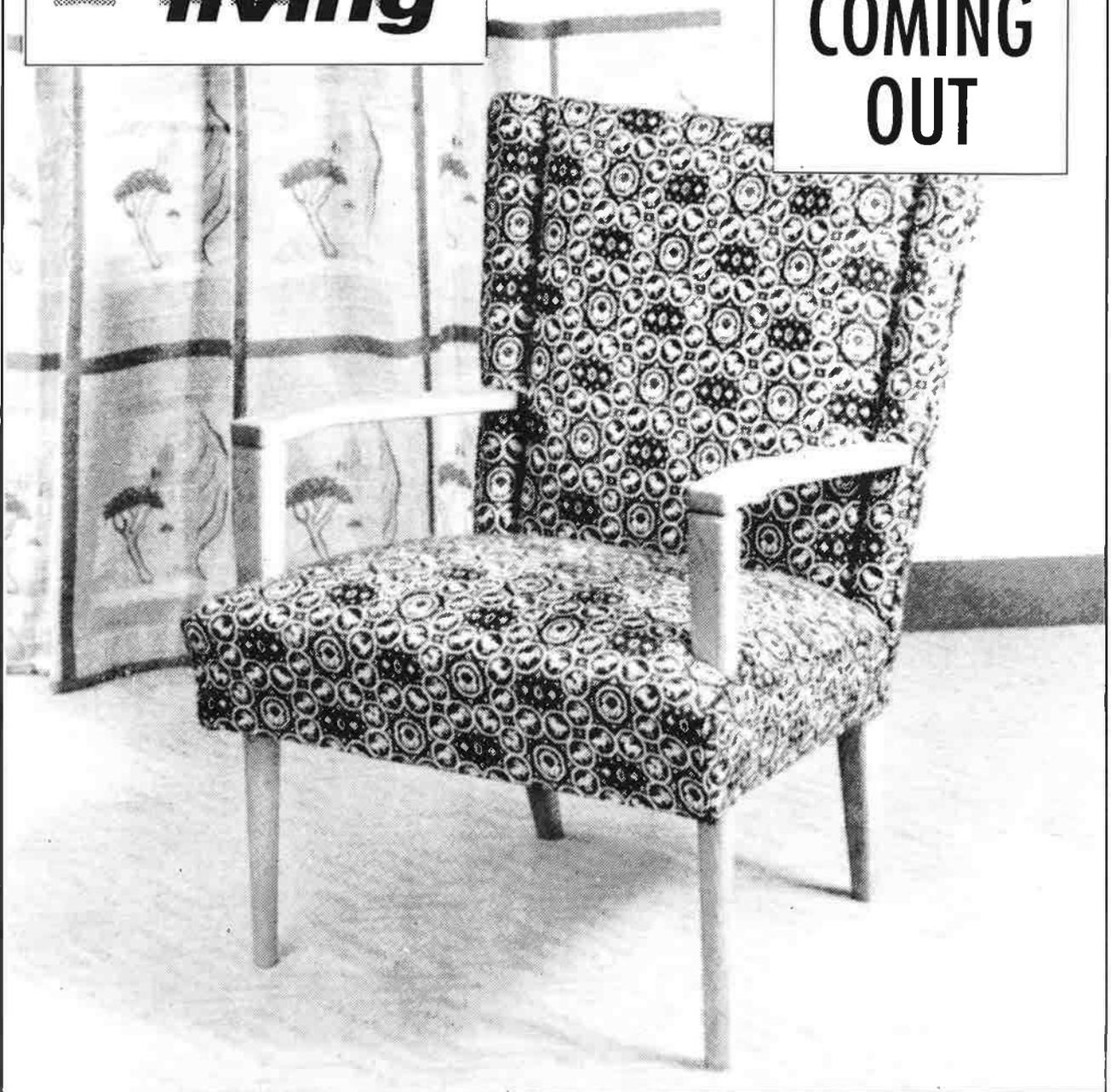
If you want more than 10, call us.

Please forward this completed form to PLWHA Inc. (NSW), PO Box 1359, Darlinghurst NSW 2010. Make all cheques payable to PLWA Inc. (NSW). Donations \$2 and over are tax deductible. We will send you a receipt.

SIGNATURE _____ DATE _____

HIV *living*

**COMING
OUT**



It's common for those of us with HIV to feel isolated. But a support group can bring us out of ourselves and draw us together. Call us to find out more about joining one.

• **SUPPORT PROJECT (02) 283 3222 or 283 2453**

AN INITIATIVE OF THE AIDS COUNCIL OF NEW SOUTH WALES INC. (ACON)